

FAULT A PRIMER ON RACE, SCIENCE AND SOCIETY LINES

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Science, Race and Ethics

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The use of racial and ethnic categories in the conduct of research has resulted in deep divisions in the scientific community in South Africa. Given our history of racial segregation and the subsequent democratic dispensation in a nonracial country, this type of division ought not to occur in the twenty-first century. Good science ought to be based on strong ethical principles. This chapter will explore the delicate relationship between science and ethics. As a point of departure, the historical origin of racial classification will be briefly discussed, as it is integral to understanding the ethics of racialised science.

A historical perspective

In 1795, a German professor of medicine and anthropologist, Johann Friedrich Blumenbach (1752-1840), building on the work of others, used the term “Caucasian” to describe one of his five races of man. The others were Malaysian, Ethiopian, Native American and Mongolian. According to Blumenbach, Caucasians originated from the region of the Caucasus mountain range that runs from the Black Sea to the Caspian Sea. Georgia, Russia, Azerbaijan and Armenia are located in this region, east of Turkey. His work, although inaccurate, was perceived to have given credence to the concept of biological race. He also introduced racial hierarchy when he described the Caucasians as “the most beautiful race of men”.¹ In current literature, “white” people in different parts of the world are still inaccurately referred to as “Caucasian”.²

It is evident that since the 1790s, and well into the twentieth century, science has been used to confirm and authenticate folk beliefs about human differences in health, intelligence, education and wealth based on race. This coincided with the

practice of slavery and the need to justify this practice. Samuel Cartwright was a medical doctor who believed that blacks were biologically suited for slavery.³ In his time, he focused on medicalisation of aspects of slavery. For example, the behaviour linked to a slave attempting to run away from a master was termed “drapetomania” and was regarded as a disease. In the nineteenth century, some scientists attempted to quantify differences amongst races by measuring head size and other body parts (anthropometry) to document race inequality.⁴

By the end of the nineteenth century, greater attention was paid to the size of the brain, and there was a belief that race differences could be measured in this way. In the early twentieth century, intelligence tests became a major interest amongst scientists who were looking for ways to document differences in brain function between black and white people.⁵

Before and during World War II, unethical experiments were conducted on various ethnic groups globally. Eugenic practices (involving attempts to create a genetically pure race and improve the human gene pool) in Nazi Germany in the 1930s are well documented. However, similar eugenic practices occurred in the United States in the early 1900s. Between 1907 and 1927, 16 states in the USA had conducted sterilisation as a eugenic practice on the disabled, alcoholics, the poor and criminals; most of these people were black.⁶ During World War II, the Germans experimented on Jewish people in the Nazi concentration camps, and the Japanese conducted experiments on Chinese prisoners of war.⁷ After World War II, the rejection of eugenics, which had supported laws aimed at sterilising people presumed to have bad genes, resulted in a compelling critique of race as a biological concept.

In the early 1900s, several clinical trials were conducted predominantly on black people in various parts of the world. Although motivated by science, there was a level of exploitation involved in recruiting vulnerable poor black people, who were objectified in the name of science. The Tuskegee Study discussed below was one such example.⁸

Exploitation of research participants

In Alabama, in 1932, 400 African American men with syphilis and 200 healthy men (controls) were enrolled into a research project. The researchers wanted to establish what the natural history of syphilis would be if it were left untreated. Doctors were still arguing amongst themselves whether syphilis affected “blacks” and “whites” differently.⁹ At the time, there was no specific treatment for the disease.

The men were told that they had to come to the clinic regularly for physical examinations, blood tests and other tests, like lumbar punctures (where a needle is inserted into the back to obtain a spinal fluid sample). In return, they were given free rides into town, free hot lunches at the clinic, free treatment for diseases other than syphilis, and they were offered a free burial, in the event of death.

By 1945, when penicillin was discovered and was found to be effective against syphilis, the drug was deliberately withheld from this group of men. The researchers continued with their study, and the men had no idea that they were part of a research project. A study that was meant to last a year continued for 40 years. It was only in 1972 that the story was exposed in *The Washington Post* and *The New York Times*. By then, many of the men had died, many of their wives were infected with syphilis, and some of their children were born with syphilis.¹⁰ The Tuskegee Syphilis Study became a source of great distrust of research by African Americans in the United States and one of the greatest research embarrassments of the United States government.

The USA was not the only country where people of colour were treated unfairly and atrociously in the name of science. In South Africa, the case of Wouter Basson comes to mind.

Project Coast (1981-1995)

In the 1980s, the apartheid-era government started a chemical and biological warfare research programme called Project Coast. It was headed by the cardiologist, Wouter Basson. The project had a number of civilian front companies, including Roodeplaat Research Laboratories and Delta G Scientific. The programme recruited about 200 scientists from around the world to develop various drugs, vaccines and weapons. Although this was a secret project for many years until it was shut down in 1994, testimony provided at the Truth and Reconciliation Commission (TRC) hearings revealed the type of research being conducted by medical doctors and scientists alike.

Some of the projects had a strong eugenic focus and were based on race.¹¹ The anti-fertility research projects aimed at developing anti-fertility drugs that could be administered to black women in South Africa without their knowledge. Dr Schalk van Rensburg was in charge of the fertility projects and he indicated that “fertility and fertility control studies comprised 18% of all projects”.

According to Van Rensburg, Basson had motivated for this project, as he believed the drugs could be used to prevent female soldiers from becoming pregnant. He also

wanted to contain the birth rate in the refugee camps. Van Rensburg did testify that black people were physiologically, biochemically and endocrinologically identical to white people, so it would be difficult to develop a contraceptive that would work on one race group and not on another. However, if the delivery of the drug were skewed – for example, if it were made available at clinics serving the black population – this would be possible. It appears as though animal experiments were prioritised for fertility research. Dr Jan Lourens had developed equipment for animal experiments – including a restraint chair for baboons and a “stimulator and extractor” to obtain semen from baboons.¹² The contraceptives was never developed.

Another plan involved the development of chemical warfare agents that could be used for crowd control during the apartheid era. Testimony from Dr Adriaan Goosen at the TRC hearings indicated that research conducted at Roodeplaat Research Laboratory (part of Project Coast) aimed to develop a bacterial agent that would selectively kill black people. Project Coast and its research activities were closed down after the democratic government came to power. Several charges have been brought against Dr Wouter Basson, and he was found guilty of unethical conduct by the Health Professions Council of South Africa in December 2013.¹³ However, despite the numerous charges against him, he has repeatedly raised legal challenges to rulings made against him. Another South African case involving exploitation of women in the name of research was conducted at the University of Witwatersrand by Dr Bezwoda.

The Bezwoda case

Dr Werner Bezwoda was an oncologist in private practice with a part-time appointment at the University of Witwatersrand in Johannesburg. During the 1990s, he conducted research on a sample of South African women, most of whom were classified as black. They all had advanced breast cancer and were attending a public hospital. The treatment that he claimed was beneficial was high-dose chemotherapy combined with a bone marrow transplant, rather than standard-dose chemotherapy. Such high doses of chemotherapy, used on women who were very ill, surely caused severe side effects and unimaginable suffering. His research attracted international attention because he presented his results at international oncology conferences and published in international scientific journals.

However, the apparent “beneficial” effects reported from his studies could not be replicated in other patients with breast cancer in other parts of the world. It was later discovered that his research was fraudulent. He had conducted his research on poor South African women without ethics approval and without their informed consent. Furthermore, the protocols for some of his research were written long after

he had actually finished the work.¹⁴ Although Dr Bezwoda lost his position at Wits University, and his fraudulent research was exposed, the harm caused to his patients and to other patients around the world could not be reversed. That was a violation of the cardinal rule of medicine: first, do no harm.

The three case studies above illustrate the historical relationship between scientific research and race in different contexts. However, science and race are more closely intertwined in a wide range of research contexts.

Race as a research variable in science

Scientists in all fields of study around the world have been using racial categories in research for decades.¹⁵ In most cases, the racial categories have their origin in political systems and government entities such as Statistics South Africa that keeps population data for public health and other purposes. In many cases, societies like ours have become so entrenched in racial categorisation that we often categorise ourselves and our research participants without thinking about the scientific basis of our actions or the implications of our research findings. This type of institutionalised thinking in the world of science has often remained routine and without challenge.

A major field of science that has challenged the social construct of race has been human genetics. Genomic research has established that any two individuals, irrespective of ethnicity and “race”, are 99.9% the same genetically.¹⁶ The 0.1% difference, although small, accounts for almost 3 million differences in DNA that result in differences in health, behaviour and other traits from one person to the next. Interestingly, there is more genetic difference between individuals of the same race than there are differences between individuals of different race groups. While genomic research offers great hope for healthcare, there are still many challenges, as most genomic studies have only included “European ancestry populations”.¹⁷

It has long been established that “race” has no biological basis. What is often referred to as “race” may be linked to skin colour (whites, blacks), ancestral origin (South African of Indian origin), geographical location (Asian), language (Spanish, French, isiXhosa) or culture. In genetic terms, phenotype and genotype are important words to understand. Genotype usually refers to our DNA – the genetic make-up that we inherit from our parents. Phenotype refers to our physical appearance – how we look as a result of genetically inherited characteristics and other factors.¹⁸ A wide range of environmental factors impact on our external physical appearance – exposure to the sun, nutrition, poverty, access to cosmetics and cosmetic procedures, mental and physical health, stress, and many others. Phenotypic differences form the basis for dividing people into so-called racial groups.¹⁹ In conducting scientific research on humans, these biological facts must be taken into account, as they impact on

decision-making around the ethics of research. The various ways in which people are categorised into race groups vary around the world. In North America, a black person is anyone with known African ancestors; this is referred to as the “one drop rule”.²⁰ It was only in the 2000 census in the USA that individuals were allowed to identify two or more racial ancestries.

In fact, Thomas Jefferson, a founding father and the third president (1801 to 1809) of the United States of America, had a great impact on the development of racialised science. He is regarded as the first American to write publicly about the “Negro”, and he suggested that the natural inferiority of the Negro was a rationalisation for slavery. This was documented in his book, *Notes on the State of Virginia*. He called on scientists to prove his attempted justification of slavery.²¹ Consequently, an enormous body of “scientific” research was devoted to proving that human differences in health or intelligence are due to race. The controversial Sport Science article on cognitive functioning of “coloured” women is regarded as racialised science and was potentially an addition to this collection of “research” until it was retracted in response to a petition led by Professor Barbara Boswell of the University of Cape Town that was supported by thousands of scientists and academics in South Africa. The section that follows illustrates why this study is regarded as unscientific and therefore unethical.

Ethical research must be scientifically sound

All research we conduct must be in accordance with the highest standards of ethics. So what makes scientific research ethical?²²

- ◆ Collaborative partnership
- ◆ Social value
- ◆ Scientific validity
- ◆ Fair selection of participants
- ◆ Risk-benefit ratio
- ◆ Independent ethics review
- ◆ Informed consent
- ◆ Respect for participants

Collaborative partnership

Engaging with communities prior to commencing research is an important point of departure in all types of scientifically valid research. Do the communities regard the research question as important to health and well-being in their context?²³ How can the researcher-community partnership maximise co-creation of knowledge

production? A meaningful community engagement process in the Sport Science study would have clarified the community's values, culture and social practices.²⁴ Shared responsibility for research requires an authentic community engagement process. In the Sport Science study, an important question ought to have been raised about why five "white" women researchers had selected a group of sixty "coloured" women as their study participants. Perhaps this question would have been raised by the Cloetesville community itself, had the full research team met with them prior to the research. Diversity in the demographics of a research team is important in reducing power imbalances and exploitation in research.

Social value

The social value of research is measured by the improvement in health and other social circumstances of human beings. Important questions that must be considered before conducting research include:

1. To whom will the research add value?
2. What is the potential benefit to potential stakeholders?
3. How can the social value of the research be enhanced via communication of results?
4. How will the research impact on existing healthcare infrastructure?

Scientific validity

Scientific rigour is important in any scientific discipline. As a starting point, ethical research must be scientifically sound. The research question must be relevant, and preferably one that has not been answered before. For example, we may want to know how many people in the Western Cape visit traditional healers or complementary practitioners rather than doctors in day hospitals, and why. In the Sport Science study, it is not clear why there was a research interest from a group of sports scientists in establishing the cognitive functioning of a group of "coloured" women in Cloetesville.

Cognition refers to a broad range of activities carried out by the human brain – thinking, knowing, reasoning, remembering, analysing, planning, decision-making, amongst others.²⁵ Research on cognitive function is usually conducted by psychologists, neurologists, neurosurgeons, neuroscientists, psychiatrists and other mental health practitioners. In reviewing this study, an important query that ought to have been raised by the Research Ethics Committee (REC) was why cognitive function was being explored by this research team of sports scientists. Furthermore, was there any expertise in neuroscience or mental health amongst them, and what instruments were being used to measure cognitive function?

When we conduct research, we must follow rigid methodologies that are rational, precise, relevant and reproducible. We can gather from the published article that the Montreal Cognitive Assessment tool was used to measure cognitive function in South African research participants, despite the fact that it was previously found to yield flawed results.²⁶ The risk here is that healthy adults would be misclassified as impaired; the use of this tool would therefore be inappropriate. It was clear that the methodology used in such a study would be flawed. To establish this, an expert in cognitive function ought to have reviewed the research protocol submitted to the REC.

In any study, establishing a good research question requires a solid literature review. If the literature review supports the need for research in the field of study, proper selection of the research population is critical.

Fair selection of participants

Researchers need to define populations, describe the study sample and discuss their findings. In South Africa, the racial categories described by Statistics South Africa are often used in data collection. And this is where “race” often becomes an important factor. In an attempt to answer a question around access to healthcare, a scientist may decide to design his/her study and conduct it in a specific province or socioeconomic region. As a legacy of the Group Areas Act in South Africa, it might well be the case that more people of a specific apartheid-defined “racial group” live in that region. Collecting data in such a study may include a question around “race” and ethnicity. Here, race would be used as a social category, not a biological category.

What do we mean by race? Or should we be asking about ethnicity? Are these two terms interchangeable? Race refers to physical appearance – skin colour, eye colour, hair type. Race is socially constructed in an attempt to group together individuals, but it implies biological difference between groups so classed, and genetic homogeneity within heterogeneous groups.²⁷ The racial categories are broad and overlapping, and individual research participants do not fit clearly into one group or the other, due to genetic diversity within the same “race” group.²⁸

Ethnicity refers to commonality of cultural factors, including nationality, language, culture, traditions, beliefs, food habits, religion and so forth. In other words, ethnic groups are clusters of people with common cultural traits. It is sometimes useful to use these categories to study “sociocultural and traditional values” within groups. They can help to cluster individuals coming from geographically distant regions, but will not indicate the extent of admixture in a person with admixed ancestry.²⁹

Race and ethnicity are often and incorrectly used interchangeably in research. Such “imprecise use of race and ethnicity data as population descriptors in genomics research has the potential to miscommunicate the complex relationships among an individual’s social identity, ancestry, socio-economic status, and health, while also perpetuating misguided notions that discrete genetic groups exist”.³⁰ Smedley and Smedley argue that ethnicity and culture “bear no intrinsic connection to human biological variations or race”.³¹

Some argue that collection of data on race may be justified under the following circumstances:

1. Reporting race can indicate if the population studied reflects the diversity of the population to whom results are applicable.
2. Race may indicate (together with other factors) if randomisation has been successful.
3. Racial disparities exist in risk factors, treatment and health outcomes – so race may be necessary to research inequity.³²

Some studies ask for self-identified race while others make assumptions about race based on observation and recording of data by fieldworkers or data collectors. It is therefore important for a REC to clarify how data on race is to be collected if justification has been provided to use it as a variable in research. This is important because we are one human species and there are no subspecies. There must be a 15% difference genetically between groups to declare a subspecies.³³ In humans, the genetic difference between the so-called races is less than 1%. As far back as the 1790s, Blumenbach, despite his unscientific approach to categorising humans into five groups, confirmed the unity of humanity (monogeny) at a time when plurality of humans (polygeny) was popular. Although he had controversial ways of describing Caucasians, and much of his work is regarded as inaccurate today, he reported no subspecies in his work on humans. He described differences amongst humans, but attributed these to differences in climate from a geographic perspective. Blumenbach also noted heterogeneity within groups.³⁴ This is in sharp contrast to the Sport Science article, which refers to coloured women as homogenous.

Other terms are also used in scientific articles to denote categorisation of humans or ancestry. The term “Caucasian” is often used, as is the term “Non-Caucasian”. The usual implication is that Caucasians are white people of European origin. However, as we have seen historically from the work of Blumenbach, use of the word “Caucasian” is unscientific and a misnomer.³⁵ It refers to people who originated

from Georgia, Russia, Armenia and Azerbaijan, not all Europeans and certainly not all “white” people. The use of terminology such as “black” and “African” to describe heterogeneous populations is simply inaccurate.³⁶

Data analysis and the interpretation of research results are of critical importance. Even if a statistically significant relationship between a health outcome (such as high blood pressure) and race is found, it does not establish causality. Health outcomes have multiple causes that are interrelated, and so race and ethnicity influence health through complex pathways.³⁷

Risk-benefit ratio

In any research project, it is important for a REC to identify the potential risk of harms and the potential benefits of conducting the research. This calculation is based on balancing the ethical principles of beneficence and non-maleficence. Risks include potential physical, psychological and social harms. There is a strong psychological component associated with identity in South Africa. The Sport Science study had the potential to cause both psychological and social harm to “coloured” women in Cloetesville. This could have been predicted by both the research team and the REC. However, the publication caused harm to all “coloured” women in South Africa. This was not appreciated by the reviewers at the scientific journal that published the article. The benefits from conducting the study remain unclear, given that the study was methodologically flawed. Clearly, a risk-benefit analysis was required by the research team when the study was conceived, when it was reviewed by the REC and the funder, and later by the journal reviewers and editorial team.

Scientists are often so immersed and invested in their research that they may lose objectivity. For this reason, it is important to involve an independent group of peers and others to review a study. This is the role played by the Research Ethics Committee (REC). Scientific rigour, risks and benefits, and the fair selection of study participants are important criteria that a REC will look for when it reviews research.

Independent ethics review

Before research studies are conducted anywhere in the world, they are usually submitted to a REC for review. This committee should be made up of a group of people from diverse backgrounds in terms of gender, ethnicity and scientific expertise. In addition, there should be lay representation of the communities involved in the research. The role of the REC is to protect the rights of research participants by ensuring that:

1. the study is based on good science, and
2. ethical requirements are met – voluntary consent is obtained, confidentiality is maintained, and participants are not exploited or stigmatised as a result of the research.

In order to fulfil this role, the REC has to review the study protocol and related documents, such as the questionnaire, interview guides and consent documents. In the twenty-first century, REC members must also keep abreast of advances in genomics in order to fully appreciate the new scientific variables that will be introduced into research. The qualifications, diversity and expertise of the researchers or research team are also reviewed. During the review, consideration of the following ethical principles is important:

1. Respect for participant autonomy
2. Beneficence (do good)
3. Non-maleficence (do no harm)
4. Justice (fairness)

In the case of the Sport Science study, the research location was Cloetesville. Demographically, the population of Cloetesville is reported to be 88.1% “coloured”, according to the Statistics SA Census 2011 data. This ought to have been a trigger to the REC to raise a query as to why this particular group of women was chosen for a Sport Science study, and more importantly, why this group was chosen to test cognitive function. It should also have been a trigger to look at the questionnaire to see if data was being collected on race, and if so, if it was being used as a biological research variable.

Irrespective of the responses received from the researchers, a critical question that needed to be raised with them was whether the findings of the study would stigmatise the predominantly “coloured” study population in any way. This question is based on the ethical principle of non-maleficence, or doing no harm. In the course of research, it is important that participants are not harmed while new knowledge is generated.

The quantum of social harm is much higher when civil society attempts to draw conclusions about the cognitive function of specific groups of people based on race. A diversely constituted REC and research team would be sensitive to this dynamic. After all, apartheid in South Africa was justified by past leaders of this country on the basis of difference in intellectual function. Hendrik Verwoerd (prime minister 1958-1966) is quoted in *Apartheid: A History* as follows: “There is no place for [the Bantu] in the European community above the level of certain forms of labour ...

what is the use of teaching the Bantu child mathematics when it cannot use it in practice?”³⁸ Given our history, any study that attempts to link race with cognitive function must be carefully considered by a REC. This is why the National Health Research Ethics Council (NHREC) in South Africa has guidelines for who should serve on a REC. Members should represent the demographic profile of the country to ensure sensitivity to local context in order for a proper risk assessment to be made. Another important ethical consideration in research is whether it is possible for informed consent to be obtained from potential research participants. This is established by looking at the consent documents and patient information leaflets submitted by a research team.

Informed consent

Based on the principle of respect for autonomy, all participants in research must provide voluntary informed consent before research begins.³⁹ This requires the researcher to provide detailed information about the study to the participants. Usually a process of community engagement should precede the start of the research, as described earlier. This allows for relationship-building to establish trust between the research team and participants.⁴⁰ The REC plays a pivotal role in ensuring that a community-engagement process is in place before research starts.

Furthermore, the consent language and information provided to participants is important. Information provided must include the purpose, methods, risks, benefits and alternatives to participating in the research.⁴¹ Most importantly, the language used must be clear and easily understood by the participants. In the case of the Sport Science study, potential research participants needed to be approached in advance to discuss why the study was being conducted amongst “coloured” women in the Cloetesville area. It would have been necessary to explain that their cognitive function would be measured, what cognitive function means and why it was important to measure this aspect of their lives. Given the historical sensitivity to cognitive function, more specifically to intelligence, in different “race” groups in South Africa, and because of previous research where difference in intelligence was linked to race, this study ought to have been reviewed with a high level of concern.

In 1994, the book *The Bell Curve*⁴² created debate in academic circles. Hernstein and Murray, the authors, attempted to shape public policy based on their flawed research alluding to the intellectual inferiority of some groups. The book represents late twentieth-century thinking about the presumed genetic inferiority of African Americans, women and poor people. Cognitive function and intelligence are poorly understood terms that are closely related and therefore easily confused. Intelligence is poorly defined and generally difficult to measure. There are both formal and

informal theories of intelligence. Lay conceptions of intelligence are broader than psychologists' conceptions. Studies have shown that lay persons view intelligence as consisting of verbal, practical problem-solving and social competence abilities. Many tests, including intelligence quotient (IQ) tests, do not measure all these components.⁴³ As such, it would have been very important for the researchers to justify why and how they were going to measure cognitive function, both to the REC and to the potential study participants. Obtaining valid consent from potential participants is a sign of respect for persons.

Respect for participants

It is an ethical obligation to ensure that respect for participants is maintained throughout the study. Seeking consent for participation is based on such respect. Keeping study information confidential to the extent possible is also a component of respect. Ensuring that participants are not stigmatised as a result of research is yet another way of showing respect. Conducting a study on cognitive function in a specific group of people in South Africa had the potential for harm, considering the sensitivity around testing aspects of mental function in different race groups. After a study, providing feedback to communities about the findings is essential. Media reports on the Sport Science study clearly indicate that the communities in the Western Cape felt disrespected and hurt by the conclusions drawn, and the generalisation to all "coloured" women in South Africa was rightfully severely criticised.

Once a study has received research ethics approval, it may start recruiting participants. At the conclusion of the study, publication is an ethical responsibility.

Action: Policy and publication with scientific integrity

How scientists report research findings is important, because it has the potential to reinforce prejudice in terms of race and ethnicity, thereby reducing the value of scientific research.⁴⁴ Generalisation from small studies to whole populations is also problematic. This is especially important in the wording of the title of the study. Consider the Sport Science article, "Age- and Education-Related Effects on Cognitive Functioning in Colored South African Women". Although the study was conducted on 60 women in the Western Cape, the title of the published article refers to "coloured" women in the country in general. And because "cognitive functioning" is used, the implications for social harm, including stigmatisation, is significant.

The publication of this study was also, to a large extent, the responsibility of the journal and its reviewers, as well as the editorial team involved at the publishing

house. There was a failure to critically appraise the methodology of the research, as well as the ethics, in terms of social harm. The subsequent retraction of this article is testimony to the flawed review process. Ultimately, however, the research team ought to take full responsibility for the outcome of their research. It remains unclear why a team of sports scientists would be concerned with the cognitive function of “coloured” women.

Researcher integrity is an ethical obligation. When communities have been harmed by research, both the REC and the research team may be seen to have failed those communities. Presented here are principles towards improving accuracy in publication involving diverse populations:

- ◆ In research it is important to describe the study population in a scientifically valid way, using geographical location and specific descriptors.⁴⁵ We have learned from the International HapMap project to refer, for example, to the “Yoruba in Ibadan, Nigeria” or the “Han Chinese, in Beijing, China”.⁴⁶
- ◆ When race or ethnicity are used as research variables, the reason for its use must be provided when a project is submitted to a Research Ethics Committee (REC) for review. If there is no explanation, it is the duty of the REC to raise a query and request an explanation.
- ◆ The REC also needs to explore whether race will be assigned by the researcher based on observation (unscientific) or if the data will reflect self-identified race or ethnicity.⁴⁷ Race based on observation is problematic, because it is based on assumption and bias.
- ◆ When racial or ethnic differences are found in research, all conceptually relevant factors, including a range of social factors, must be explored.⁴⁸ Genes and the environment are usually inseparable.
- ◆ It is a good idea to engage with communities early in the course of research to establish how the potential research participants and community members would like to be described in the research study, in related scientific publications, and in the popular media.
- ◆ Provide a summary of research findings in simple language for the media to encourage accurate reporting.⁴⁹
- ◆ Avoid broad descriptions such as Asian, European or African without explanation.⁵⁰
- ◆ The use of broader descriptions such as Caucasoid, Mongoloid and Negroid is unscientific.⁵¹

Conclusion

Use of race as a variable in scientific research is generally problematic, because racial groups based on physical characteristics are not genetically discrete or scientifically meaningful. Race has been imposed by history and should not be legitimised by science. It is important to distinguish between race as a biological category and race as a social category.⁵² There may be a place for race as a social category when there is a need to examine access to societal goods and resources, because “inequality renders race an important social policy concern”.⁵³ Racial categories may be useful in studying whether the perceived race of patients correlates with health disparities.⁵⁴ More importantly, research is needed to examine “the social attitudes and institutions that perpetuate the idea of race”.⁵⁵ Although genomics research holds great promise for the future, reporting human genomic variation must not be conflated with racial and ethnic groups.

Immigration and intermarriage in a globalised world have led to increasing heterogeneity everywhere. The number of people of mixed or diverse ethnicity is growing exponentially, making labels like “coloured” overwhelmingly inaccurate and the use of race as a biological variable in research unscientific.⁵⁶

Science and ethics are inextricably linked. There can be no science without ethics. Researchers and research teams must take final responsibility for ensuring that their scientific work is conducted ethically and with integrity.

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